

DHDD Newsletter – August 2021



A Note from the DHDD Director:

Dear DHDD Partners,

I hope you are doing well and staying healthy. I know that many of you and the audiences you serve share my concerns about the COVID-19 Delta variant. This can add more worry to an already-stressful situation. Vaccination is the best way to protect people from hospitalization and death and also decreases spread (although it doesn't eliminate it). This is important to protect our children under 12 who are not able to be vaccinated and people with reduced vaccine uptake due to being immunocompromised. As CDC learns more about this variant, it will be posted to our [COVID-19 website](#). Please continue to check this site for important information.

On a more positive note, I am excited about a number of opportunities that have recently been awarded. A new five-year cycle has begun for the Disability and Health Promotion Branch's state-based disability and health programs under Cooperative Agreement DD21-2103. This new cycle will build upon existing programs aimed at improving the health of Americans with intellectual and developmental disabilities and mobility limitations. Additionally, funding for two disability-focused national centers – Special Olympics and the National Center on Physical Activity and Disability – will also allow these organizations to continue to promote the health of people with disabilities. Child Development and Disability Branch funds also were recently awarded to continue to provide support for better understanding Fragile X syndrome (FXS) to improve the lives of children and adolescents with FXS, and their families. You can read more about all three of these in the newsletter below. Such great work and I am excited to see what these new funding cycles bring!

All the best,
Georgina

In the Spotlight

CDC Awards \$4 Million Cooperative Agreement to Build on the Work of the FORWARD FXS Natural History Study

A \$4 million cooperative agreement to "Characterize the Natural History of Fragile X Syndrome to Inform the Development of Intervention and Outcome Measures" was awarded to Dr. Elizabeth Berry-Kravis of Rush University Medical Center by CDC.



The five-year study funded by the grant will build on the foundation of the [Fragile X Online Registry With Accessible Research Database \(FORWARD\)](#) in collaboration with [CDC's Study to Explore Early Development \(SEED\) Follow-up Study](#). It will involve in-person standardized assessments to observe cognition, language, behavior, and autism diagnosis. The study will also

explore the practical, financial, and psychological impact that caring for a family member with Fragile X syndrome (FXS) has on caregivers and siblings.

The project aims to better define the natural history of FXS and determine meaningful outcome measures that will improve the lives of children and adolescents with FXS, and their families.

United Hospital Fund Profiles Five Providers Offering Integrated Family Care

CDC funded a recent report by the United Hospital Fund, in collaboration with ChangeLab Solutions. The report describes how five service providers in New York, New Hampshire, and Michigan have implemented the emerging Integrated Family Care model, examining both their successes and challenges. Integrated Family Care aims to address the physical, behavioral, and social needs of families with young children who face significant adversity caused by social determinants of health. Providers that adopt elements of the model work to coordinate medical care, behavioral health care, and social services, with the goal of promoting long-term family and child well-being.

[Read more about “Profiles in Integrated Family Care”.](#)

New Funds for Disability and Health State Programs

CDC has launched a new phase of funding for its [Disability and Health State Programs](#). These programs work to improve the health and quality of life among people with disabilities through the adaptation and implementation of evidence-based strategies in their communities. Funding began August 1, 2021.

Over the next five years, CDC will invest more than \$5 million to facilitate activities at nine existing sites and one new site (Georgia State University Foundation Inc.) within 10 states. The 10 sites include the following:

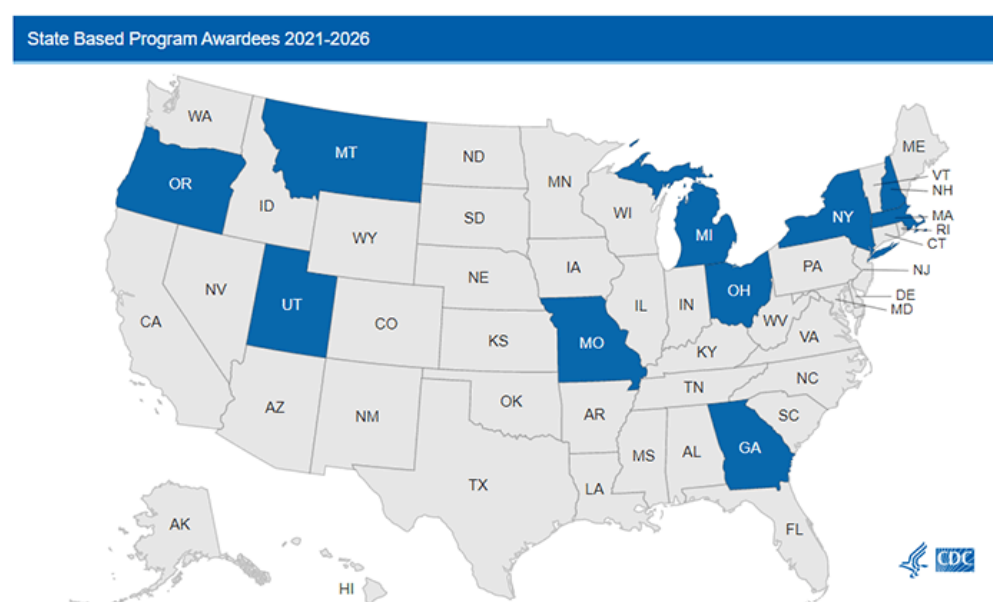
- Georgia State University Foundation Inc.
- Massachusetts Department of Public Health
- Michigan Department of Health and Human Services
- The Curators of the University of Missouri on behalf of UM-Kansas City
- Montana Department of Public Health and Human Services
- University System of New Hampshire
- Health Research Inc./New York State
- Ohio State University
- Oregon Health and Science University
- Utah Department of Health

This funding opportunity will facilitate

- Engagement with high-quality routine preventive healthcare,
- Adoption of healthy lifestyle behaviors, and
- Early identification, management, and control of chronic disease and mental health conditions among people with intellectual and developmental disabilities and people with mobility limitations.

Across the United States, an estimated 1 in 4 adults lives with a disability. This investment by CDC will support more inclusive state programs, communities, and health care to help people with, or at risk for, disabilities be well and active in their communities.

Please email dhddodrequests@cdc.gov with any questions.



COVID-19 Pandemic: Helping Young Children and Parents Transition Back to School – Spanish Feature Available

Many early care and education programs stayed open during the COVID-19 pandemic to provide needed care. But for many families, the pandemic meant keeping their children at home. Transitioning back to early childhood programs or school— or starting them for the first time— can be hard for children and families. Transition in a time of physical distancing, masks, and extra stress is extra hard. The [feature describing what parents, teachers, and administrators can do](#) to help children make a successful transition to in-person learning and care is now [also available in Spanish](#).



Optimizing EHDI Surveillance Practices and Information Systems

The 39 jurisdictions funded under four-year Cooperative Agreement DD20-2006 (*Improving Timely Documentation, Reporting, and Analysis of Diagnostic and Intervention Data through Optimization of EHDI Surveillance Practices and Information Systems*) have successfully completed the first year of this latest project. During Year 1 all the funded jurisdictions successfully completed a range of activities that are helping to ensure all infants receive essential follow-up diagnostic and intervention services. This included advanced surveillance, data analytic, and evaluation activities.

New Resources


New EHDI Data Available

The Type and Severity data for infants identified with hearing loss in 2019 is [now available online](#). For these latest 2019 data, updated tables and graphs with improved summaries have been included.

New Resources for Caregivers of People with IDD

Healthcare providers work hard to help their patients stay healthy and safe from COVID-19. When talking with patients who have intellectual and developmental disabilities (IDD), it's especially important to make sure the message is simple and clear. These tips can help providers talk to patients with IDD about COVID-19.

[Find this guide and more materials here!](#)

Stay safe from COVID-19


A guide for caregivers

COVID-19 is challenging to explain, live through, and communicate about. As a caregiver, you work hard to help the person you care for stay healthy and safe during this difficult time. These materials were created to help you share important information about COVID-19 — and make the tough moments a little easier.

We've created videos, posters, social stories, and cut-out activities so you can choose the materials that work best for your situation. The materials cover 5 basic topics:



- Getting a COVID-19 shot
- Wearing a mask until a few weeks after your last COVID-19 shot
- Keeping a safe distance until a few weeks after your last COVID-19 shot
- Washing your hands
- Getting a COVID-19 test

Videos
You can watch the videos together to visualize specific ways to stay safe — like wearing a mask and social distancing until a few weeks after your last COVID-19 shot — and apply these ideas to your own daily routine.

Posters
The posters can help the person you care for remember to practice healthy habits. Post them in the kitchen, living room, or other places where you spend time together. You can also share them in schools, workplaces, and other group settings.

Social stories
You can read the social stories together to reinforce habits like wearing a mask and learn what to expect in new situations, like getting a COVID-19 test or vaccine. Some of the social stories are interactive, so you can fill in the blanks together and personalize the story. For example, you could use the "How I keep a safe distance" social story to remind the person you care for to practice social distancing at their workplace or school.


Cut-out activities
These activities are a great way to review the steps of handwashing or get ready for a COVID-19 test. Cut out the pictures together and help the person you care for place the steps in order.

New Resources for Providers with Patients who have IDD

A new guide for caregivers was recently developed to provide some tips based on what caregivers have found helpful in having important, and sometimes difficult, conversations about COVID-19.

[Find this guide and more materials here!](#)

Stay safe from COVID-19



Talking to Patients who have Intellectual and Developmental Disabilities about COVID-19

As a healthcare provider, you work hard to help your patients stay healthy and safe from COVID-19. When you're talking with patients who have intellectual and developmental disabilities (IDD), it's especially important to make sure your message is simple and clear. These tips can help you talk to patients with IDD about COVID-19.

Helpful resources for patients and caregivers

CDC has created materials to help caregivers communicate with people with IDD about COVID-19.

The **Stay Safe from COVID-19** materials cover basic topics like getting the vaccine, wearing a mask, keeping a safe distance, washing your hands, and getting a COVID-19 test. To learn more or download the materials, visit cdc.gov/coronavirus/2019-ncov/communication/toolkits/people-with-disabilities.html.



Keep it simple.
Stick to short words and sentences when you can. Many people with IDD process information in a literal way, so it's best to avoid metaphors and figures of speech.

Show that you're listening.
The COVID-19 pandemic has been hard for everyone, but people with IDD may face additional challenges. Show your patient that you understand by listening to their concerns, then repeating what you've heard in your own words.

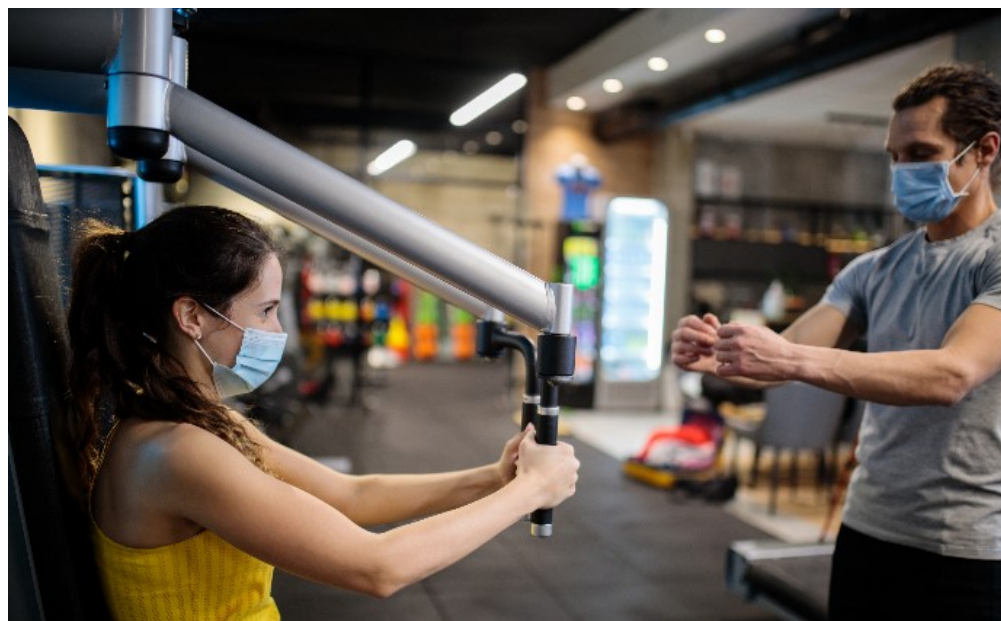
Say it in pictures.
When you recommend protective behaviors like wearing a mask or keeping a safe distance, use literal, realistic images to help your patients visualize those behaviors. When possible, break behaviors down into a series of steps, using 1 image to illustrate each step. You can also use visual schedules with pictures to help patients understand what to expect in new situations.

Include everyone in the conversation.
If your patient brings a caregiver or support person to their appointment, be sure to include everyone in the conversation. When you're asking questions or sharing information, always talk to your patient directly. Then, check in with their caregiver or support person to learn more and make sure everyone is on the same page.

Repeat key takeaways.
For people with IDD, repetition is key. As you're wrapping up your visit, take time to repeat the main ideas you want your patient to take away from the conversation.

Partners Release Inclusive Fitness Survey

Lakeshore Foundation and NCHPAD are interested in learning if people with disabilities feel welcomed in fitness spaces. Responses will be used to help tell the story nationally and spark innovative change and opportunity around inclusive fitness. The organizations have developed a short survey, which will take about 5 minutes to complete. The survey is open to U.S. residents, age 18 or older who have a disability or chronic condition.



Lakeshore Foundation and NCHPAD are asking partners to share the survey broadly amongst your constituents. Please share in your listservs, newsletters, social media platforms, and other print and electronic dissemination strategies to help reach the most people. The survey can be completed directly through Facebook or a survey link in English and Spanish.

Sample text to share:

Lakeshore Foundation and NCHPAD are interested in learning about if disabled people feel welcomed in fitness spaces. Your response and input will help us tell the story nationally and spark innovative change and opportunity for inclusive fitness.

Complete the survey on Facebook and share with a friend: <https://survey.app.do/inclusivefitness>

Complete the survey online in English or Spanish: <https://bit.ly/2VJmsnq>

Publications

New Report: Evaluation of the Feasibility and Perceived Value of Integrating *Learn the Signs. Act Early.* Developmental Monitoring Resources in Early Head Start

A new study published online in the [Early Childhood Education Journal](#), presents findings from the evaluation of the use of [Learn The Signs. Act Early. \(LTSAE\)](#) resources in Early Head Start (EHS) programs in four states. The data indicate that EHS management, staff, and parents found the use of LTSAE resources valuable, feasible, and helpful in providing shared language to effectively discuss child development. These findings inform EHS and other early education programs that wish to enhance developmental monitoring, screening, and referral.

Please feel free to share this communication broadly within your networks. If you are not currently a subscriber, click the button below to subscribe.

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DHDD'S mission is to lead inclusive programs to optimize the health and development of children and adults with, or at risk for, disabilities.

National Center on Birth Defects and Developmental Disabilities
Division of Human Development & Disability

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